



Session 301: Innovative Approaches to Reducing HIV-Related Stigma Across Rural Communities

2020 National Ryan White Conference on HIV Care and Treatment
August 2020

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Sonya Hunt Gray
HIV/AIDS Bureau (HAB) Rural Health & HIV Workgroup
Health Resources and Services Administration (HRSA)

Vision: Healthy Communities, Healthy People



Health Resources and Services Administration (HRSA)

Overview

- Supports more than 90 programs that provide health care to people who are geographically isolated, economically or medically vulnerable through grants and cooperative agreements to more than 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities
- Every year, HRSA programs serve tens of millions of people, including people with HIV/AIDS, pregnant women, mothers and their families, and those otherwise unable to access quality health care



HRSA's HIV/AIDS Bureau (HAB) Vision and Mission

Vision

Optimal HIV/AIDS care and treatment for all.

Mission

Provide leadership and resources to assure access to and retention in high quality, integrated care, and treatment services for vulnerable people with HIV/AIDS and their families.



HRSA's Ryan White HIV/AIDS Program

- Provides comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV
 - More than half of people with diagnosed HIV in the United States – nearly 519,000 people – receive care through the Ryan White HIV/AIDS Program (RWHAP)
 - Funds grants to states, cities/counties, and local community based organizations
 - Recipients determine service delivery and funding priorities based on local needs and planning process
- Payor of last resort statutory provision: RWHAP funds may not be used for services if another state or federal payer is available
- 87.1% of Ryan White HIV/AIDS Program clients were virally suppressed in 2018, exceeding national average of 62.7%



Source: HRSA. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2018; CDC. HIV Surveillance Supplemental Report 2018;21(No. 4)



HAB Rural Health & HIV Workgroup's Mission

To provide support and resources to HAB recipients and stakeholders to assist in the delivery of optimal care and treatment for people with HIV in rural communities.



Agenda

- I. Institute Overview
- II. Characteristics of Stigma
- III. NASTAD – Addressing Stigma in Rural Communities to Advance HIV Care
- IV. University of Virginia - Peer Coach Program
- V. Montgomery AIDS Outreach – Community-Based HIV Stigma Project
- VI. Q&A

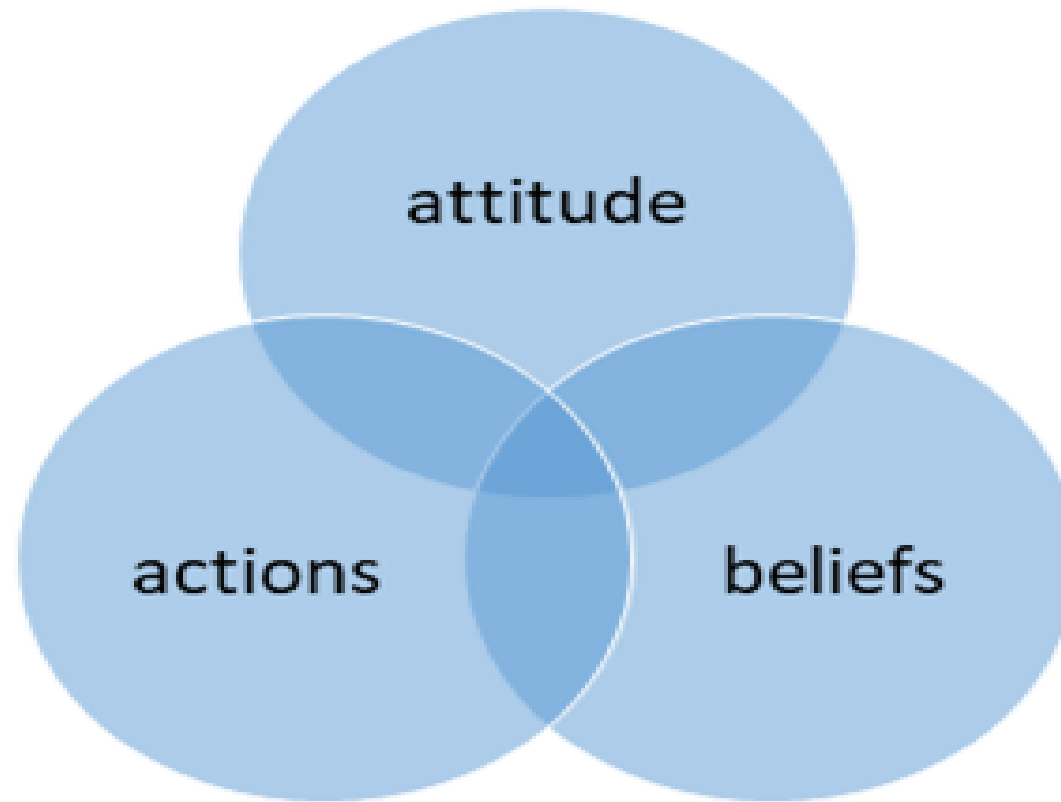


Institute Overview

- 101 Session - An Overview of HIV-Related Stigma and HIV Care and Treatment in Rural Ryan White HIV/AIDS Program Settings
- 201 Session - Federal Resources and Community Initiatives to Reduce HIV-Related Stigma in Rural Areas
- 301 Session - Innovative Approaches to Reducing HIV-Related Stigma Across Rural Communities



Characteristics of Stigma



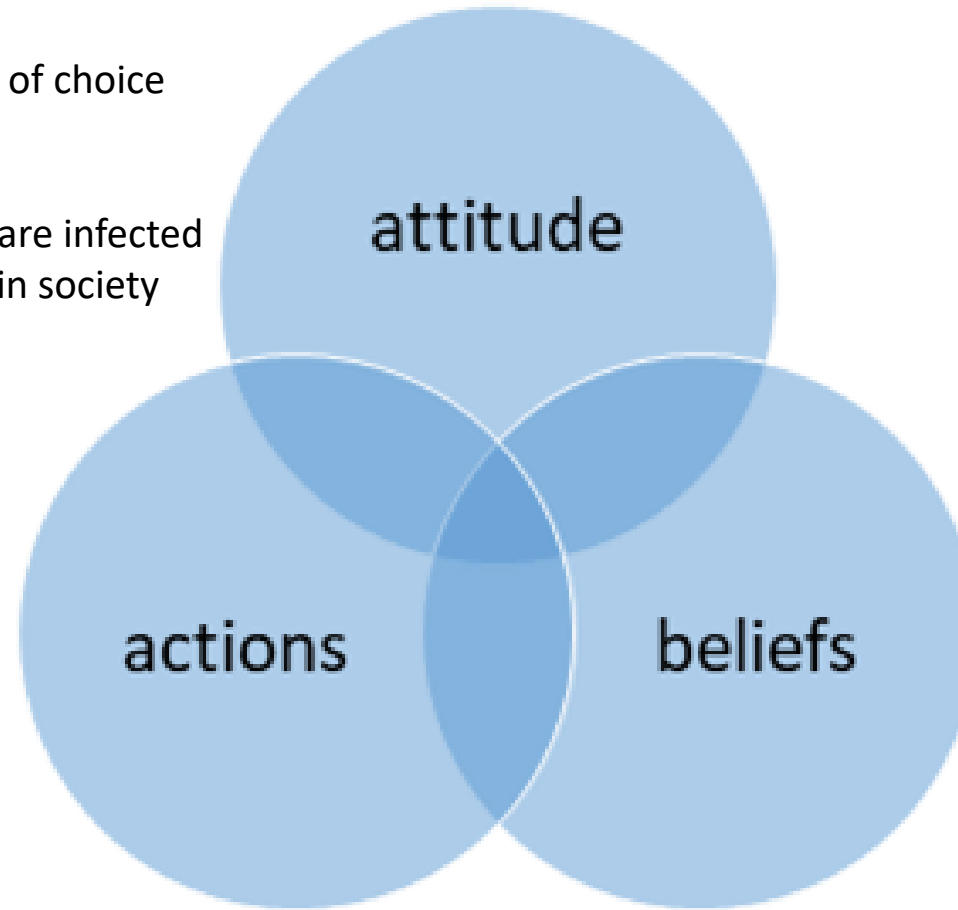
Characteristics of Stigma

Attitude:

- Discredit a person or a group
- People deserve to get HIV because of choice
- Fear
- People perceived to be infected
- People associated with those who are infected
- Coupled with marginalized groups in society
- Self-stigmatization - shame

Actions: -

- Discrimination
- Social ostracism
- Refusing contact
- Violating confidentiality
- Diminished support
- Violence



Beliefs:

- Socially unacceptable
- Only certain groups can get HIV
- Stereotypes
- Influenced by myths

Contact Information

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HIV CARE & TREATMENT

NO LOOK

Anti Stigma Campaign

Medical Advocacy and Outreach—Montgomery, Alabama

NO LOOK

LESLY MCINTYRE

PEER MENTOR/CONSUMER SUPPORT SPECIALIST

DISCLOSURES

Lesly McIntyre has no relevant financial or non-financial interests to disclose.

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Commercial support was not received for this activity.

LEARNING OUTCOMES

At the conclusion of this activity, participants will be able to:

- 1. Describe the No Look anti-stigma campaign**
- 2. Explain the collaborative activities**
- 3. Summarize how a campaign is planned**

About the Presenter



Lesly McIntyre (He, Him, His) serves as a Peer Mentor-Consumer Support Specialist for Medical Advocacy and Outreach. Lesly is driven by his passion to share his experiences with individuals LWHIV to overcome societal barriers and stigma by encouraging them to live “Positively Positive”. His goal is to be prepared to always articulate and provide knowledgeable responses to help PLWHIV overcome internalized stigma and have a greater knowledge of their disease state.

LEAD ACADEMY

Leadership, Education & Advocacy Development

Developed as a grassroots anti-stigma initiative created by and for people living with HIV as a result of being awarded \$25,000 through the SPARK (Southerners Promoting Awareness and Real Knowledge) Grant.

Goal of LEAD ACADEMY

To prepare members of LEAD Academy for the Launch of the
NO LOOK Anti-Stigma Campaign
NOTHING ABOUT US WITHOUT US

How did we get started?



Recruitment activities included:

- Putting flyers up in the clinic about LEAD Academy
- Word of mouth
- Discussions at CAB (Consumer Advisory Board) meetings

Recruitment resulted in a total of 13 participants:

- 6 males
- 7 females including 1 self-identified transwoman.

What was our plan?



Promote FACT: HIV has “NO LOOK” throughout the city

- Billboards
- Flyers
- Rack Cards
- Montgomery City Transit System

Members of LEAD Academy were photographed and the images were displayed on these different mediums

What did we do?



Provided learning and interactive activities to foster and promote Empowerment, Education, Engagement and Embracing life LWHIV.

- **Empower**— **PLWHIV** to tell their story with confidence and become advocates for themselves and strong leaders
- **Educate** –How to host educational programs, engage in public speaking activities, develop a true working knowledge to help overcome myths with facts, and teach others risk reduction strategies
- **Engage**- Peer to Peer interaction and learning
- **Embrace** –themselves as a “person first” and that HIV is merely a part of their life story

Prep Activities



- The MAO Behavioral Health Team provided a series of trainings to help LEAD members develop strategies to deal with societal stigma while also beginning to process and overcome internalized stigma and how to respond to community responses.
- Vic Sorrell (Gilead Services Community Liaison) provided HIV education and helped LEAD members to develop a better understanding of their disease state that could be articulated to individuals when presenting for speaking engagements.
- LEAD Members met once or twice monthly to foster the bonding process amongst members. During these meetings members provided feedback on personal experiences, brainstormed ideas and served as peer support to one another.

Prep Activities



- LEAD Members completed trainings with the consumer support specialist on how to read body language when in the community to know how to engage the audience they conducting educational activities.
- LEAD Academy members developed a survey to gauge the knowledge of members of the general population regarding HIV vs Myths and societal ideas. These surveys were administered at various MAO events.

Implementation Activities



- Focus Groups
- Storytelling
- Participated in MAO Community Education Department activities collaboratively
 - Administered surveys.
 - Distributed risk reduction resources (condoms, dental dams, etc.)
 - Provided educational pamphlets and cards.

NO LOOK !



- NO LOOK campaign was a collaborative effort by the leaders to combat the stigma of knowing that HIV has a look.
- NO LOOK is a conversation starter on what HIV looks like in the rural community. How can you tell who has HIV by looking at them?
- The intent of NO LOOK was to dispel the myth that someone who is HIV positive has a “LOOK” and is not clean person.

Participant Video





Thank You!

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HOW TO CLAIM CE CREDIT

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ryanwhite.cds.pesgce.com

POSITIVE LINKS

REBECCA DILLINGHAM MD/MPH

**HARRISON DISTINGUISHED ASSOCIATE TEACHING PROFESSOR OF
MEDICINE, UNIVERSITY OF VIRGINIA**

ON BEHALF OF OUR TEAM

DISCLOSURES

Rebecca Dillingham

- **Receives grant/research support from: Gilead Sciences, Inc.; Virginia Department of Health; NIH**
- **Provides consulting services to Warm Health Technology, Inc**

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LEARNING OUTCOMES

At the conclusion of this activity, participants will be able to:

- 1. Describe the elements of the Positive Links mental health app for PLWH**
- 2. Identify performance measure outcomes**
- 3. Summarize impact on HIV-related Stigma**

Provided learning and interactive activities to foster and promote
Engagement and Embracing life

- **Empower**— **PLWHIV** to tell their story with confidence and become advocates for themselves and strong leaders
- **Educate** –How to host educational programs, engage in public speaking activities, develop a true working knowledge to help overcome myths with facts, and teach others risk reduction strategies
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Stigma and PositiveLinks:

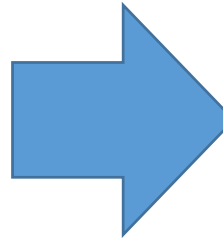
Opportunities for mHealth Interventions to Reduce Stigma for PLWH

HIV Care Challenges Rural VA

- **Stigma**
- Transportation
- Poverty
- Isolation
- Alcohol/drug use
- Mental health challenges



mHealth in rural Virginia?



Edit Text Messages

Schedule 1

Click to select or unselect the days messages are sent:

Mon	Tues	Wed	Thurs	Fri	Sat	Sun
✓	✓	✓	✓	✓	✓	✓

Enter time and text message (160 characters or fewer):

11	:	00	AM	▼	Get your ass up and take your 5 meds.
09	:	00	PM	▼	Did you take your 2?
	:		AM	▼	

[Add another message](#)

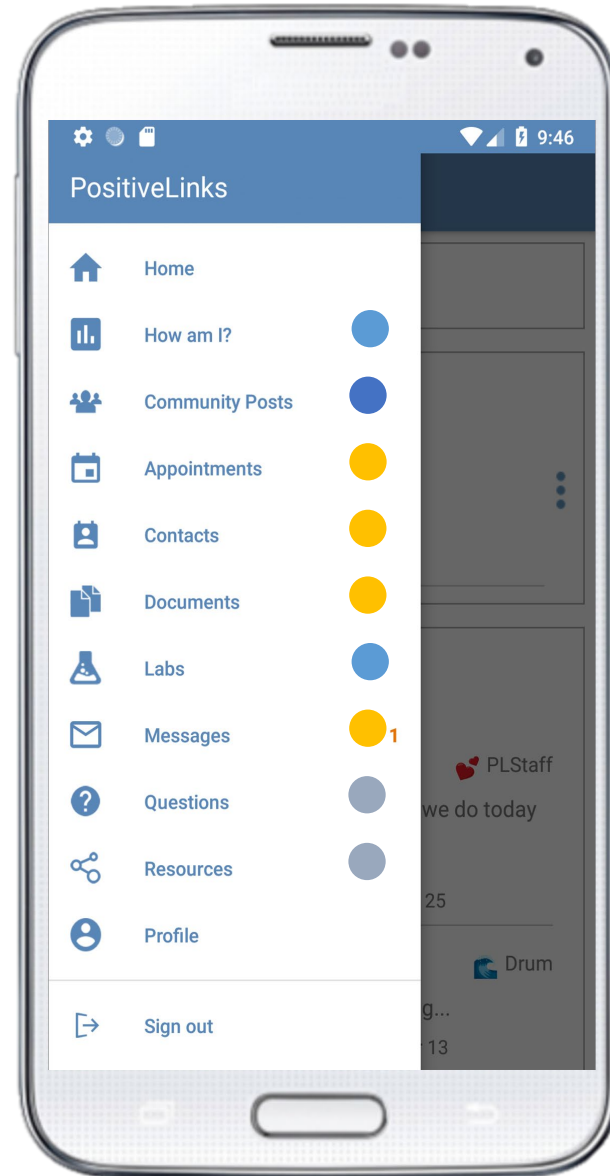
[Clear Schedule](#)

Perspectives on SMS Intervention

“It feels good that I can actually talk to someone every day about it. Even if it’s a machine, it feels great to know that there's someone there to affirm to me that this is a good and right thing. “congratulations” sounds good, you know?”

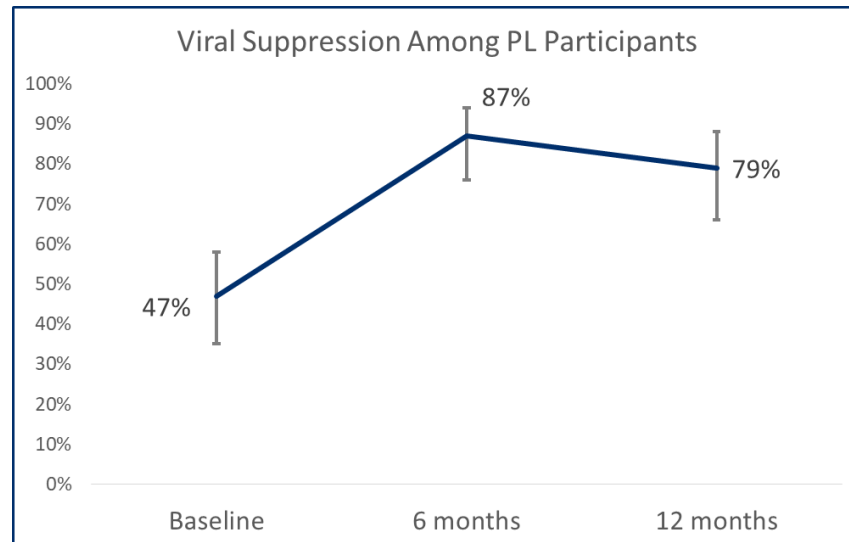
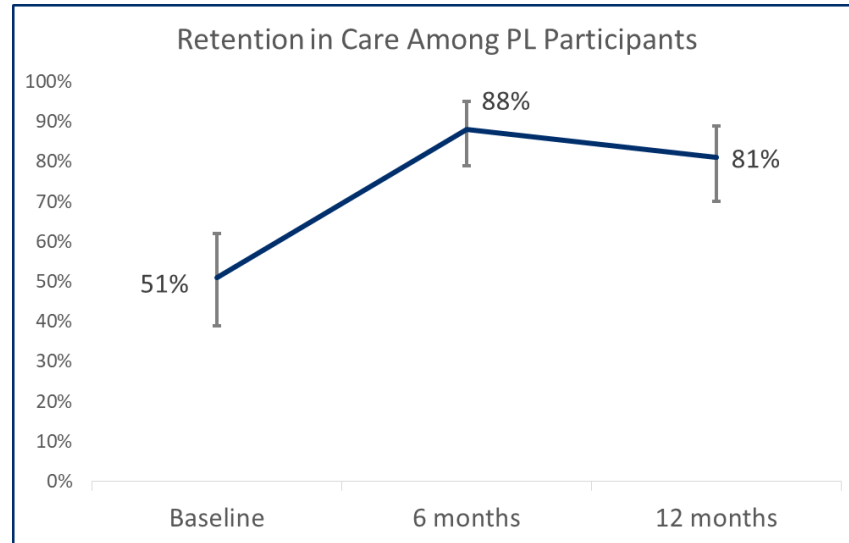
“It gave me more positive feeling about myself that I’ve done something good that day for me. Having somebody at your back is a positive thing.”

PL App Components



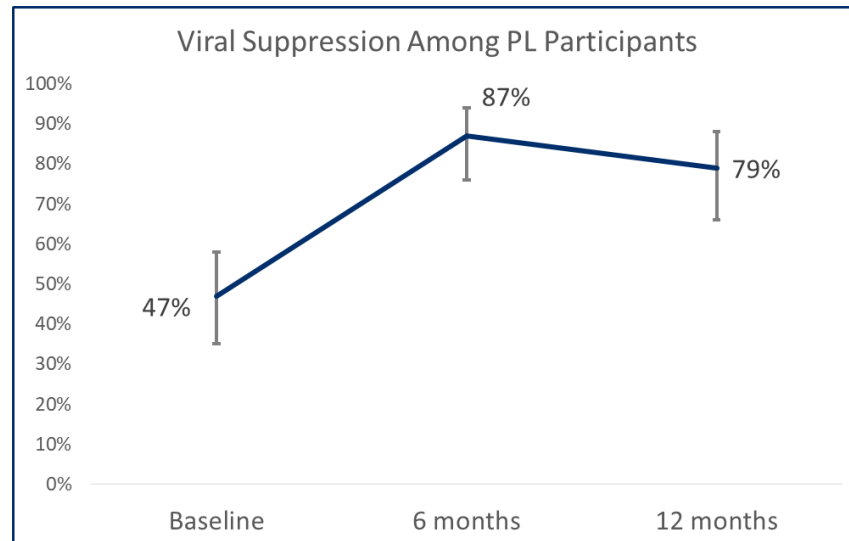
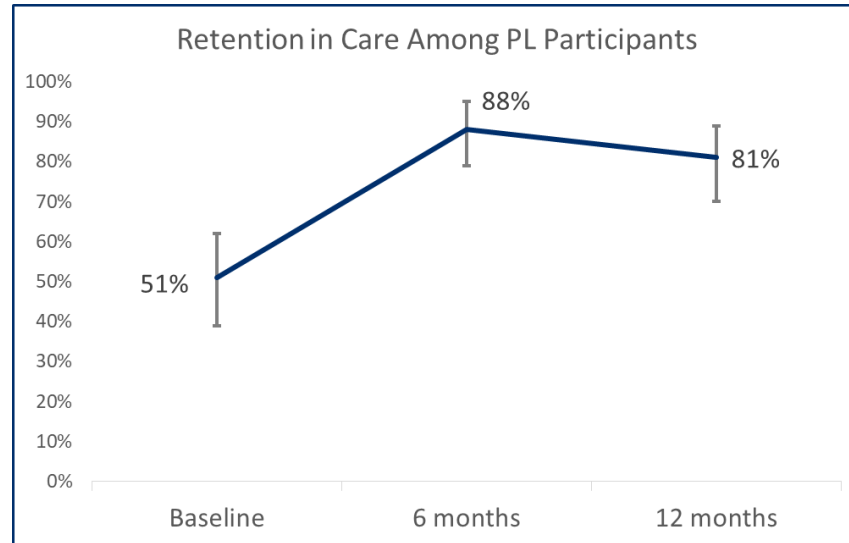
- **Self-Monitoring and Management**
- **Care Coordination**
- **Educational Resources**
- **Social Support**

PL V1.0 Outcomes



- Significant **increases** in engagement in care (top) and in HIV viral load suppression (bottom) over one year of follow-up (n=77)
- **Stigma** scores are improved with increased use of the community message board.*
- **Social support** is sought and provided regularly. **
- In app **patient-provider** messaging is a mechanism to build **rapport**.***

PL V1.0 Outcomes



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More Information about PositiveLinks

COMPENDIUM OF EVIDENCE-BASED INTERVENTIONS AND BEST PRACTICES FOR HIV PREVENTION

POSITIVELINKS

Evidence-Informed for Retention in Care

INTERVENTION DESCRIPTION

Goal of Intervention

- Improve retention in HIV care
- Improve HIV viral suppression
- Decrease HIV viral load

Target Population

- Clinic patients

Brief Description

PositiveLinks (PL) is a clinic-based smartphone app that features tailored educational resources; daily queries of stress, mood and medication adherence; weekly quizzes; appointment reminders; and a community message board (CMB). The educational resources include an orientation to the clinic, information on HIV and health, and stress reduction techniques. For the CMB, participants select user names to protect anonymity and can start new conversations or respond to older conversations. The PL team intermittently introduces new conversation topics on HIV or general well-being, and the team can communicate with the participants privately to address technical issues and assist with care coordination on the CMB. Contact information for the clinic-affiliated PL team is also included in the app. Participants were given smartphones with the PositiveLinks app installed.

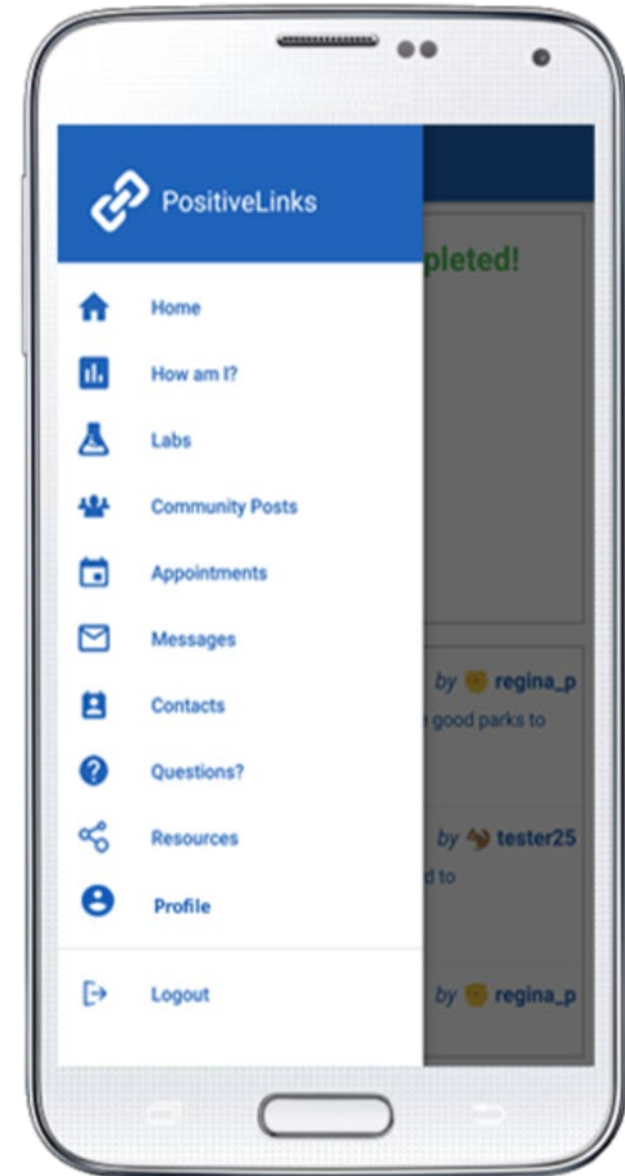
Linkage to, Retention in, and Re-engagement in HIV Care (LRC) Chapter

This chapter of the [Compendium](#) categorizes the best practices in promoting Linkage to, Retention in, and Re-engagement in HIV Care among people living with HIV, one of the priorities outlined in the U.S. National HIV/AIDS Strategy. Additional details about the LRC Chapter or the [Prevention Research Synthesis \(PRS\) Project](#) can be obtained by [contacting PRS](#).

PositiveLinks Website:
www.positivelinks4ric.com

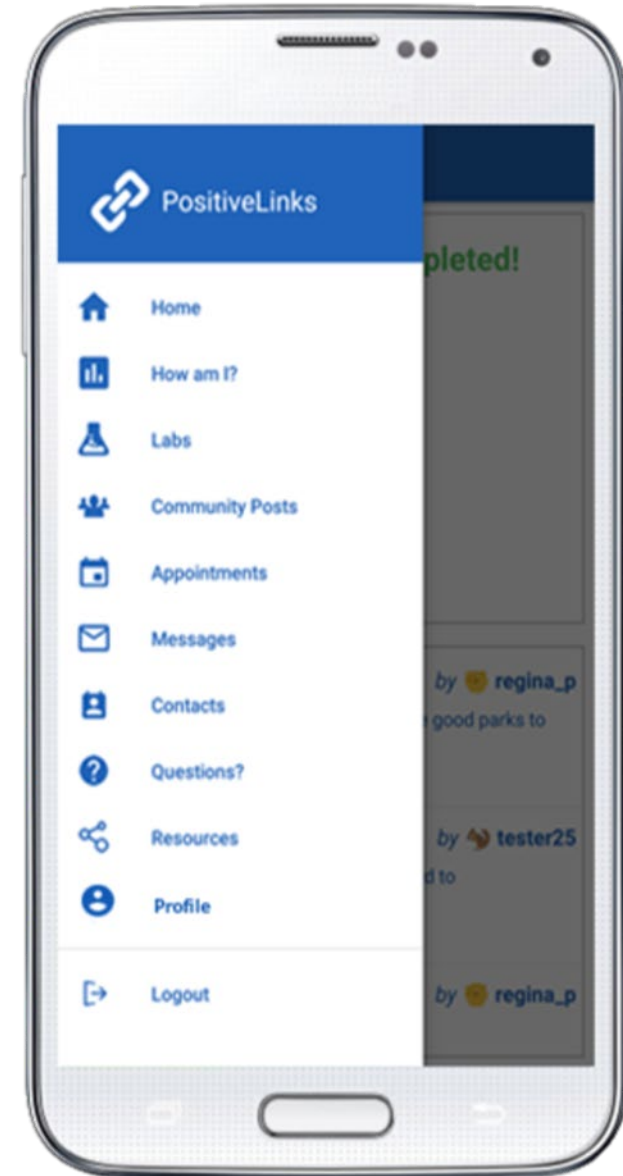
Stigma is Multi-faceted

- Individual
- Interpersonal
- Institutional
- Societal

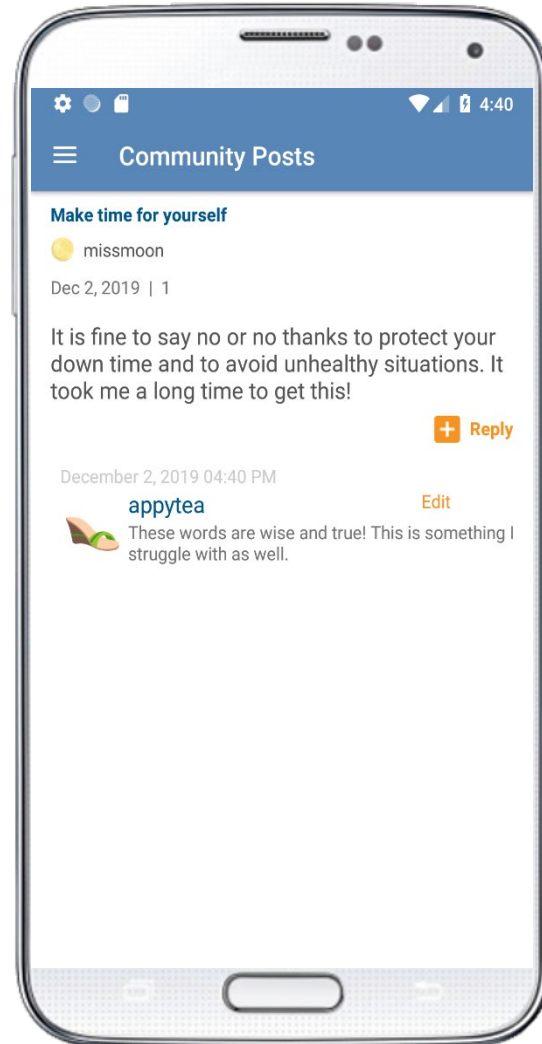
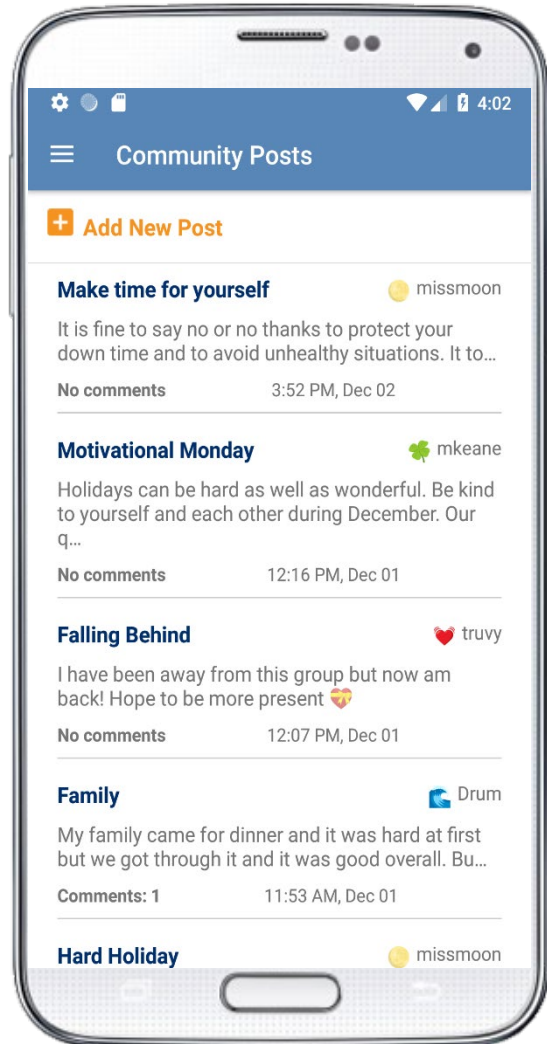


Stigma is Multi-faceted

- Individual
- Interpersonal
- Institutional
- Societal



Community Posts



“You get to talk to people who are going through exactly what you are going through. **When you are down somebody uplifts you,** when somebody else is down you can uplift them, it’s basically like one big family”

- PL Member



Addressing Stigma Through a Virtual Community for People Living with HIV: A Mixed Methods Study of the PositiveLinks Mobile Health Intervention


Tabor E. Flickinger¹ · Claire DeBolt² · Alice Xie³ · Alison Kosmacki² · Marika Grabowski¹ · Ava Lena Waldman¹ · George Reynolds⁴ · Mark Conaway⁵ · Wendy F. Cohn⁵ · Karen Ingersoll⁶ · Rebecca Dillingham^{1,7} 

Table 1 Participant characteristics

	Total (n = 77)
Gender, n (%)	
Male	49 (64)
Female	26 (34)
Transgender male to female	2 (3)
Race/Ethnicity, n (%)	
White non-hispanic	26 (34)
Black non-hispanic	38 (49)
Hispanic	6 (8)
Asian	1 (1)
Multiple races	5 (6)
Refused	1 (1)
Income compared to federal poverty level, n (%)	
0% ≤ FPL < 50%	45 (58)
50% ≤ FPL < 100%	11 (14)
100% ≤ FPL < 150%	12 (16)
150% ≤ FPL < 200%	5 (6)
200% ≤ FPL	4 (5)
Risk factor, n (%)	
Heterosexual	37 (48)
IV drug use (IDU)	3 (4)
IDU/MSM	2 (3)
Men who have sex with men (MSM)	31 (40)
Transgender	2 (3)
Don't know/missing	2 (3)

30 months; 2300 posts; 21% related to Stigma

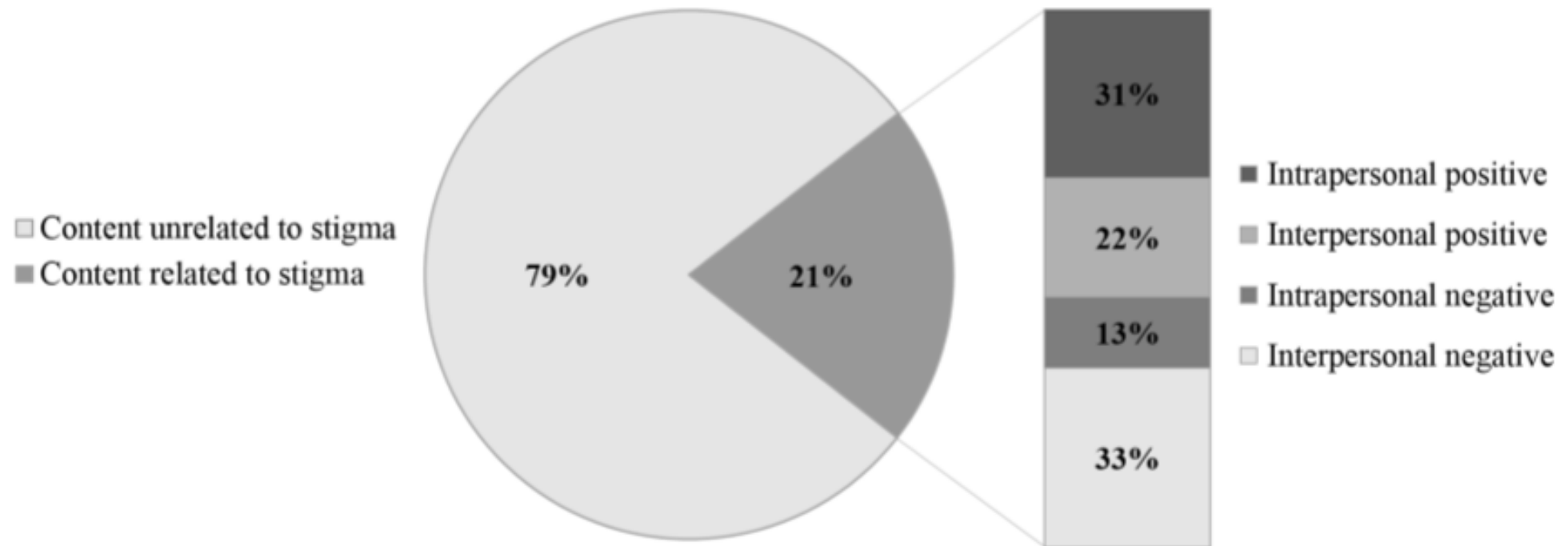


Fig. 1 Community message board coding categories and frequencies

Types of Stigma and Examples

Table 2 Stigma themes and frequency of occurrence

Stigma themes	% stigma-related posts (n)
Experiences of stigma (negative)	
Intrapersonal	
Negative framing of HIV + status	7% (26)
Lack of self-worth	6% (24)
Interpersonal	
Feelings of loneliness and isolation	9% (34)
Disrupted relationships	8% (30)
Negative past experience with disclosure	6% (24)
Negative anticipated experience with disclosure	6% (22)
Fear of transmission	3% (10)
Negative consequences of failing to disclose	2% (6)
Overcoming stigma (positive)	
Intrapersonal	
Positive reframing of HIV + status	18% (72)
Affirming self-worth	12% (46)
Interpersonal	
Finding “true” friendship/love/family	10% (38)
Positive past experience with disclosure	9% (35)
Positive anticipated experience with disclosure	3% (11)

Intrapersonal Stigma

“I just found out I’m HIV positive 5 days ago and the women I got it from treat me like s*it and I’m in a way with no family and she tell me I’ll never get nobody else bc I have HIV ... this is the first time I felt bad.” (negative)

“I strive to look at things in my life for the better and show my three children that any thing is possible if you have faith. Me being HIV positive hasn’t changed me at all.” (positive)

Interpersonal Stigma

“I feel like my supposed to be friend playing with my feelings n I opened up and told him that I hav hiv n he said he wont tell anybody but he told two of his friends and I have not stayed home in a week now.” (negative)

“Over time, my strength prevailed? I’m still growing with the new knowledge of knowing but with the support of all The Positive link family have made me realize I still have a future.” (positive)

Table 3 Interactions among participants in stigma-related threads

Thread Interactions	% stigma-related posts (n)
Positive	
Companionship	51% (204)
Positive thinking/purpose	30% (118)
Blessings/affirming God's love	13% (53)
Will to overcome	13% (51)
Neutral	
Sharing one's story	24% (95)
Instructional advice	11% (45)
Asking a question	6% (23)
Sharing need to talk	2% (6)
Negative	
Negativity	14% (54)

Stigma-Related
Threads or
Conversations

Changes in Berger Stigma Scores

Posting Category	Number in Group	Change in Stigma Score (SD)
Does not Post on the CMB	20	-0.63 (9.2)
Posts on CMB – no stigma content	15	- 3.3 (12.7)
Posts on CMB – stigma content	42	-5.1 (17.2)

- Baseline stigma scores not associated with : age, race, gender, education, income, or transmission risk.
- Baseline stigma scores positively correlated with baseline perceived stress score.
- Baseline stigma scores negatively correlated with self-efficacy to start and stay in care.
- Decrease in stigma scores associated with MALE gender.

Closing Thoughts

- Clinic-deployed mobile platform use associated with decrease in measured stigma overall (-3.9; 95% CI -8.1,0.2). May be multi-factorial with effects at intra- and inter-personal levels as well as institutional.
 - Anonymous, restricted, online support group may play an important role through creation of community acceptance and shared identity.
 - Other features may impact ability to engage with care providers, gain information, and develop coping skills.
- Larger study needed.
 - Natural Language Processing
 - RCT

Questions?



“I don’t know if many of you realize it, but **each and every one of us who uses this app is making a difference in someone else’s life** battling every day of this new journey... We all are making a difference together one day, one app, and one click at a time.”

- PL Participant

How To Claim CE Credit

- If you would like to receive continuing education credit for this activity, please visit:
 - ryanwhite.cds.pesgce.com

Addressing Stigma in Rural Communities to Enhance HIV Care Programs

Jennifer Flannagan

Manager, Health Systems Integration

Laura Pegram

Associate Director, Drug User Health

August 13, 2020



Disclosures

- Jennifer Flannagan and Laura Pegram have no relevant financial or non-financial interests to disclose.
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- Commercial support was not received for this activity.

Learning Outcomes

- At the conclusion of this activity, participants will be able to:
 1. Discuss how HIV-related stigma impacts us, the communities we are a part of, and the people we serve
 2. Locate resources and support relative to reducing implicit bias and HIV stigma as well as improving health equity
 3. Recommend technical assistance opportunities to reach priority populations and identify how they can be applied to one's work



About NASTAD

- NASTAD's mission is to end the intersecting epidemics of HIV, viral hepatitis, and related conditions by strengthening domestic and global governmental public health through advocacy, capacity building, and social justice.
- NASTAD's vision is a world free of HIV and viral hepatitis.

NASTAD's Commitment to Black Lives

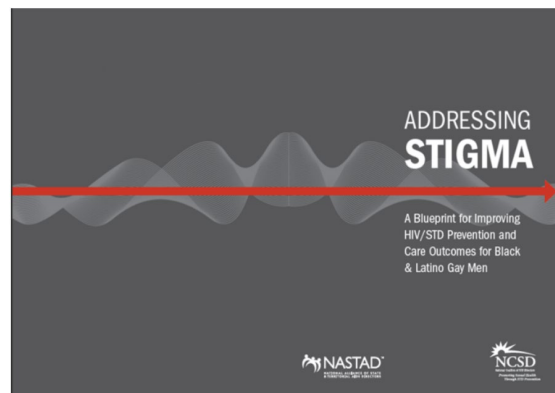
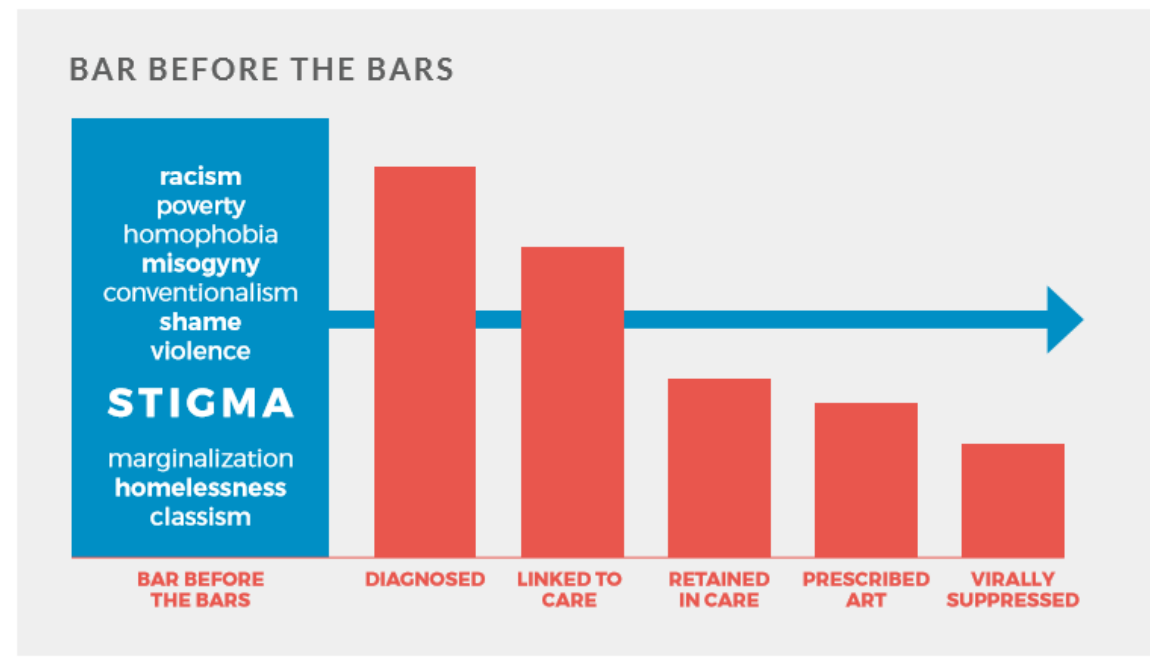
“The core of NASTAD’s mission is an unwavering commitment to social justice. We recognize that we will not end the HIV and hepatitis epidemics and related syndemics without dismantling the systems of oppression that fuel racial disparities in access and outcomes. We prioritize fighting injustices where we see them, and we value diversity and inclusivity in all forms.”



Stigma and Rural Health

- Limited awareness and education related to HIV
- Confidentiality
- Relationships
- Mistrust of health care system
- Limited access to healthcare resources
- Interconnected stigmas associated with HIV, disability, mental health, race, sexual orientation, etc.
- Social determinants of health exacerbate stigma in rural communities and serve as barriers for care and prevention:
 - Lack of services (transportation, unstable housing)
 - Lack of specialized service providers
 - Lack of Ryan White providers
 - Treatment costs for people with HIV who are low-socioeconomic status and do not live in Medicaid-expanded state

Overview of NASTAD Resources and Concepts



NASTAD's Previous Stigma Work

PRODUCTS

Funded by
MAC AIDS
Fund

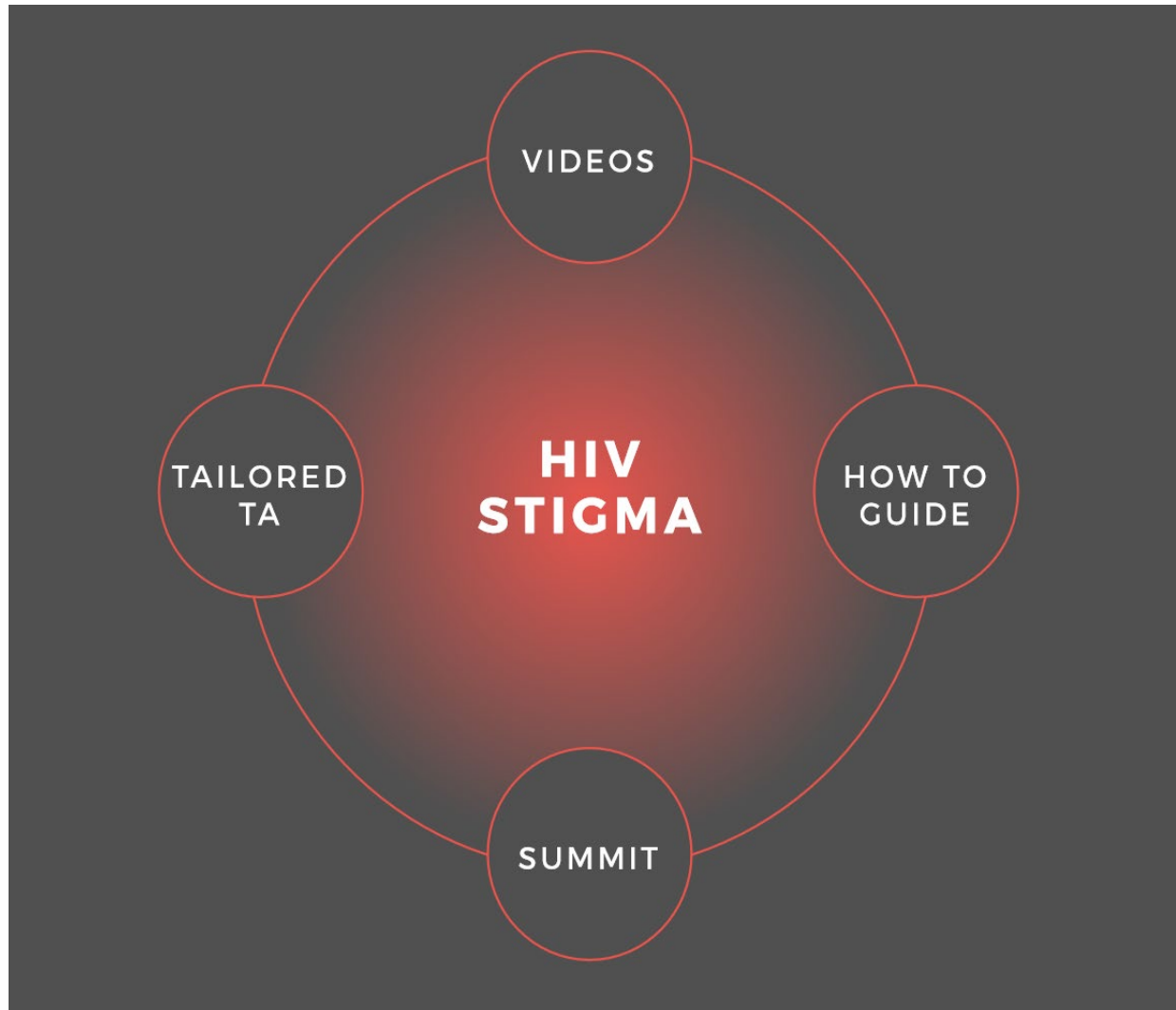
Partnership
with NCSD

Survey and
Blue Ribbon
Panel

Toolkit

Focused on optimal health
outcomes for Black and Latino
gay and bisexual men/MSM

NASTAD's Current Stigma Efforts



Stigma and Implicit Bias Video

<https://www.youtube.com/watch?v=N52epBdVN6Q>

Stigma Reduction Resources

- [Health Equity Initiative Distance Based Curriculum](#)
- [Stigma Toolkit](#)
- [Stigma Conversations Guide](#)
- [Secret Shopper Intervention](#)
- [Stigma Video Series](#)
- [HisHealth.org](#)
- [Implicit Bias Checker](#)
- [NASTAD's Commitment to Black Lives](#)

Additional NASTAD Resources



Ending the HIV Epidemic: A Plan for America -
Systems Coordination Provider (HRSA-20-089)



Harm Reduction Technical Assistance



ACCOUNTABILITY AS A PUBLIC HEALTH RESPONSE:
COVID-19's Impact on Communities
of Color

CAPACITY BUILDING ASSISTANCE (CBA)

FUNDED ORGANIZATIONS

	Northeast	South	Midwest	West
Track A: Clinical HIV Testing and Prevention for Persons with HIV	Primary Care Development Corporation	My Brother's Keeper	San Francisco Community Health Center (formerly Asian and Pacific Islander Wellness Center)	Denver Health and Hospital Authority (Denver Prevention Training Center)
Track B: Nonclinical HIV Testing and Prevention for HIV Negative People	University of Rochester	Latino Commission on AIDS	Washington University in St. Louis	City & County of San Francisco Department of Public Health
Track C: Integrated HIV Activities and Structural Interventions	New York City Department of Health & Mental Hygiene	National Alliance of State & Territorial AIDS Directors	AIDS United	Public Health Foundation Enterprises, Inc. (California Prevention Training Center)

Source: CDC Ending the HIV Epidemic: A Plan for America

NASTAD Stigma TA Examples

- Stigma Institute at the 2018 United States Conference on HIV/AIDS
- 2019 National Summit on HIV Stigma at CDC's National HIV Prevention Conference
- Michigan Harm Reduction Summit
- Statewide Drug User Health Trainings
- HIV Stigma and Implicit Bias Training
- Community Engagement of People with Lived Experience

NASTAD Staff Reflections

Thank You

thank you!

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